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Conference Paper

To understand the meaning of disability for children, parents and providers in Bulgaria, Latvia and Russia

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“Who is taking into consideration children’s rights? No-one is.” Sergei (male), 16, living at home, Bulgaria

“[I wish] that they would look at a disabled child like at a healthy one. So that they [disabled children] would have the same rights as them; so that they would be cared for.” Armands (male), 14, Latvia, living in an institution

Introduction

This research was commissioned by the UNICEF Innocenti Research Centre as part of a larger MONEE (Monitoring Eastern Europe) project covering countries in transition – the 27 nations of Central and Eastern Europe (CEE) and the Commonwealth of Independent States (CIS). The MONEE Social Report combines qualitative and quantitative material in the 2005 Publication ‘Children and Disability in Transition’ (www.unicef-icdc.org)

This paper is concerned with analysing in depth the findings from the qualitative research as the basis for recommendations that keep the voices of children, young people, families and medical and social care providers at the heart of the policy process.

This research was conducted in three countries – Russia, Latvia and Bulgaria. The reason for choosing these three countries in consultation with the networking group included the issue of children’s rights for children with disabilities in Russia which has been widely reported (UNICEF 1999, 2003). As the largest CIS country, Russia’s influence in policy and practice in other neighbouring countries is likely to be significant. Latvia was one of the CEE countries who joined the EU in May 2004 and Bulgaria hope to join the EU in 2007. Thus these three countries are in different stages of transition. The organisations and systems for supporting disabled children are likely to be influenced by political and market transitions and these three countries are interesting examples from which to explore the concept of transition as it relates to disabled children and their families.

The theoretical model that informs this research is concerned with applying the social model of disability to families rather than individuals. The structures, policies and processes that cause frustration and disappointment affect the whole family not just the disabled child (Dowling and Dolan 2001).

The social model applied in this context aims to combat the past medical and educational ideology of 'defectology' – seeing children with disabilities as defective models – which has been evidenced particularly in Russia but also all other former communist countries (Grigorenko 1998). Defectology as a professional discourse has isolated children from their families and created hostility between medical providers and parents who believe that their disabled children have been taken away from them because professionals believed it was in the best interests of their child to do so.

Many of the challenges that are described by children, young people, parents and providers are challenges that need social policy not medical solutions. Medical solutions are also very important for these children. However equally important is the need for medical and social practitioners to work alongside each other, despite their professional and theoretical differences, to provide the best social, emotional and physical opportunities for children with disabilities.

Methodology

The research was conducted by Oxford Research International in 2003 using resident researchers in the three countries. They were able to use their local networks to access families with disabled children and residential institutions and to organise focus groups and in-depth interviews. The aim of the qualitative research was to understand what it means to be physically disabled in Russia, Latvia and Bulgaria from the perspective of the children and young people themselves; their parents and the providers of services.

Focus groups and in-depth interviews were held with parents, children and care providers in February and March 2003 by resident researchers in Bulgaria, Russia and Latvia. Twelve focus groups, four per country, were organised with children with disabilities between 8-17 years. Two age cohorts (8-13 and 14-17) were developed so that younger children had as much opportunity to have their say as older teenagers. The children's disabilities included: spina bifida, muscular dystrophy, hearing and sight problems, bone tuberculosis, and cerebral palsy. The sole criteria for inclusion as a participant in the research was that the child could contribute meaningfully to the discussions. To understand the differences for children living at home and those in institutions, 18 in depth interviews were conducted - half with children living at home and half with those living in an institution.

Parents took part in nine focus groups, three per country and 18 in-depth interviews, six per country. Service providers took part in thirty in-depth interviews. In each country, there were interviews with: three educationalists, three doctors/therapists, two carers in institutions and two social workers.

In total 245 children, parents and professionals provided a range of answers to a series of open ended questions on disability, its effect on their lives and the effectiveness of services provided.

Results

These findings show what is meaningful to the recipients and to providers of services. They are illustrative rather than representative of the views of disabled children, families and service providers in Russia, Bulgaria and Latvia.

Institutional or Family Care?

Children, parents and providers generally agreed that it is better for a disabled child to live at home rather than in an institution. (Only 62 out of 124 children involved in the research were living at home).

“For me, my first home was the nursery, then school and friends from school. Now this is not like my second family, but ... how can I say it ... well, there is something wrong with that. This is a family too, we are all friends, but...” Luda, 17, living in an institution, Russia

For me, it is better to be in a family, because in this home, everyone will leave, we will separate [...] the family can support you and give you everything.” Misho (male), 13, living in an institution, Bulgaria

Nevertheless the advantages of institutional care were clearly recognised,

“It is not possible to argue that institutions [special schools, boarding schools] should be closed down. Such institutions are especially important for disabled children from disadvantaged families.” Leonards, teacher, Latvia

Institutions were seen as offering better access to educational services primarily because all necessary services were accessible on-site and financial support existed.

“Well, in the first place it is truly better to be in a family. But there are things in families which are not available [...] they don’t have the possibility to provide a computer, to give you new sports shoes, new clothes or to eat meat twice or three times a week.” Milena (female), 16, institution-living, Bulgaria

The latter point was confirmed by parents who complained that children living in institutions received more money from the state than those living at home.

“If a child is in a boarding school, then the state pays 150 lats [240 euro] for a child per month. How can it be compared [to what we receive]? If a child grows up in a family, the only money the family receives is 35 lats [56 euro] in disability allowance.” Amanda, mother, Latvia

Most parents stressed the challenges that were involved – from when the child was first born to their adulthood – in continuing to care for their child at home. They were clear that ‘the care burden’ could be improved by reforming policies and more resources and were not the fault of the individual child.

“Support for the mother is needed and she will then do everything for her child. She knows her child better than anybody else. All children are different, an individual approach is necessary. So care about the mothers and they will make their children happy.” Vera, mother, Russia

Family Dislocation

In this study, disabled children who were cared for at home often came from single parent households. The additional pressure on these families in countries where there is still significant stigma attached to having a child with a disability living with you, was discussed by both parents and service providers.

“Seniors, I mean sixty and older, are openly hostile - ‘how horrid!’ is the most frequent comment I’m used to hearing from them. They are pretty sure that if a child is ill, then parents are either alcoholics or just bad people [...] I also know one lady who tried to commit suicide after hearing bad jokes about her and her child.” Violetta, mother, Russia

“Typically fathers go into a deep depression and do not participate [in family life] any longer or, more often, leave their family.” Karina, mother, Russia

“The father of my daughter simply could not bear it. He could not accept that his child is like this, and we separated.” Vilhelmine, mother, Latvia

The sense of dislocation for the family, with both external and internal factors playing their part, also exerted pressure on siblings in the family. Siblings of disabled children were not interviewed in this study, but there many comments from professionals, and parents about how and why able-bodied children’s roles in the family changed when the disabled child was living at home.

“Usually the able-bodied children are pushed away in the family and they start to hate the child.” Ilvija, doctor, Latvia

“In a family where there is a disabled child and a normal child, the normal one is deprived of a normal childhood.” Nina, mother, Bulgaria

“I have a healthy child who helps him, but I also understand how I am burdening him.” Irena, mother, Bulgaria

“My daughter feels constant discomfort at having a disabled sister. She is not open about that with her friends.” Polina, mother, Russia

The most pressing external factor in all three countries that contributed to family dislocation was financial hardship. Many parents said they had to stay at home to care for their disabled child and thus they did not have enough money to support their family. They reported discrimination when applying for jobs and no flexibility to look after their child or children when they had succeeded in getting work. Access to appropriate support and services, poor employment opportunities which translated into financial hardship and public prejudice were the main barriers to disabled children living at home with their families.

“How is it possible with 30 leva [15 euro] in child support and 28 leva [14 euro] in invalid support [...] to feed your child, to buy textbooks, notepads and pay all the school fees?” Ralitsa, mother, Bulgaria

“.....We live only on sausages. And I’m sick of those sausages.” Justine (female), 14, living at home, Latvia

Without the support from relatives I could do nothing. It is the only thing. Both the psychological and material support from relatives [...] You feel alone and ignored. You are with your child without any special education. I was 20 when she was born. It was very hard.” Vilhelmine, mother, Latvia

“We need twice or three times more money.” Irena, mother, Bulgaria

“[What needs to improve is] the standard of living. Families should be able to take care of their children... The awareness of society, because many times families with disabled children are not treated well by their neighbours. But the most important is the financial aspect. Such a child needs more care, special medical treatment. It is very different when a family is financially stable and the mother can stay at home and take care of the child.” Kristina, institution carer, Bulgaria

Long term solutions such as better incentives for donations and other forms of financial help for disabled children were discussed by parents.

“Private firms and individuals can also help if there is a change in legislation, for example a law on sponsorship. If I am a businessperson and I have to pay the state 100 leva [50 euro] in taxes, I will prefer to give it to a child so that parents can pay for a high-quality medical examination.” Alexandra, mother, Bulgaria

Institutional Care

Children in institutions generally had little or no contact with their parents.

“I need more [love and affection], I am in a boarding school. I see my parents rarely.” Eva (female), 12, living in an institution, Latvia

While most of the children enjoyed a supportive relationship with their peer group, the major difficulties appeared when young people were due to leave the institution.

Service providers admitted that young people leave institutions badly prepared,

“They are not ready for an adult, independent life and many become alcoholics. They do not have something to call home [...] so many go nowhere. What they need is a family. And the family is not this institution...” Petr, doctor, Russia

Although children did not talk about it directly, the researchers noted that those who live in institutions appeared much less mature. Because children are cut off from family life, they do not learn how to cope with the demands of everyday life. Additionally, poor preparation for the job market meant young people were not ready to compete with the able-bodied after leaving school. Service providers blamed poor preparation for later life on the nature of institutions, insufficient funding and lack of co-operation between organizations

“We have computers but we need a specialist to teach the children how to use them. We were also thinking about a ‘young housewife room’ – a little kitchen where they can learn how to cook [...] The financing could be better; this way we could do more for their future.” Kristina, institution carer, Bulgaria

“I wish we could also offer vocational training for children, so that they could get at least some specialization, which would be useful for their future. They should also be taught the most basic things – how to go shopping, how to go to the health centre, because many do not know this.” Larisa, social worker, Latvia

“We have to use outdated equipment, so when children start working in factories and plants, they find themselves surrounded by new machines in an unfamiliar working environment; and being disabled, they already are at the bottom of the list of candidates.” Yulia, institution carer, Russia

Health Services

Children were generally satisfied with the service from the medical professions and believed that keeping themselves healthy was their most important challenge. However some young people did not define themselves as ill but different and wished to be given the same opportunities as other young people.

“I want you to write down that I don’t consider myself ill. On the contrary, it is good to live when you are young.” Valya (female), 17, Bulgaria –living at home

“[I wish] that they would look at a disabled child like at a healthy one. So that they [disabled children] would have the same rights as them; so that they would be cared for.” Armands (male), 14, Latvia, living in an institution

“You should fight to prove you are normal too.” Momchil (male), 13, Bulgaria – living at home

For parents the time of initial diagnosis of their child, was their primary point of reference. Many blamed medical services for inappropriate and late diagnosis or even for the disability of the

child. At the same time, parents across the region complained that no consequences ever followed

“He [my son] became disabled right after birth. The baby was dropped and after dislocation of vertebrae, he got spastic paresis of his lower limbs. He had a lot of operations, seven, without any result.” Tina, mother, Bulgaria

“The majority of those placed in here are being treated for our local doctors’ mistakes.” Katia (female), 17, institution-living, Russia

Most children are disabled because of doctors’ mistakes, for sure; and there is no compensation for this, no law.” Dona, mother, Bulgaria

“With paresis, if in the first three months you undertake proper physiotherapy, you can help the child a lot. But in all this bureaucracy often a year goes by before you finally get see to the specialist, who tells you what to do. And this year is already lost.” Zinta, mother, Latvia

Parents also discussed the cost of medical services. Many said they could not afford to provide their child with what they needed

“If we want to get it [rehabilitation] for free, we have to wait for two years. We do not have the money to do it sooner, so [our daughter] only receives what is offered at school – massages and gymnastics.” Niklavs, father, Latvia

“She very much needs massages. I took her to Sofia for a series of massage sessions. Paying for three sets drained me financially. People with a lot of money go there – I cannot pay.” Stefka, mother, Bulgaria

Parents in all three countries were critical of the medical profession for their lack of support, unwillingness to treat or even examine disabled children and for advising most parents to put their disabled child in an institution,

“I have heard this often: ‘leave your child and you will solve your problem. You are so young, leave your child. You will give birth to another one and you will forget this problem’.” Dona, mother, Bulgaria

“The doctor told us the diagnosis – deaf child. I didn’t know what to do. There was no help, no support.” Vilhelmine, mother, Latvia

“In Gorna Bania the doctors were very rude. They said there was no use in examining him.” Lily, mother, Bulgaria

“I went to a psychiatrist, he never touched the child or examined her. He told me that the child had mental and psychological disorders [...] and he said that every child who has hearing problems is not normal, according to him.” Aneta, mother, Bulgaria

“He [doctor] said that he [son] is with one foot in the grave: ‘Give up, he will never be useful.’ I was fighting against a wall. Now I have fought so much during those 14 years

that I have no more strength. I am ready to put all those doctors at the wall and shoot them [...] I have gone through hell.” Rita, mother, Latvia

“We were advised not to bring her up and reject her, send her to an institution.” Vera, mother, Russia

“There is no help from doctors. They do not give information to parents. Parents don’t know that their children can attend a kindergarten.” Dora, teacher, Bulgaria

There were a few examples of good practice,

“My GP, who is a paediatrician, always says: ‘I hope you do not mind, but I gave your telephone number to a mother, who has a problem, so you can tell her where to go and what to do’.” Irena, mother, Bulgaria

The medical practitioners interviewed said that it was the parent’s responsibility to care for their disabled children

“They just take the benefits and abandon them. Law for protection of children should take the parental rights away from such parents.” Borislav, doctor, Bulgaria

“Better parents (answering a question on what would encourage more children to be raised at home).” Petr, doctor, Russia

Welfare Services

Parents were frustrated and upset by the extensive bureaucracy (including disability status checks) and humiliation they experienced in their dealing with social services. Information provided and co-operation between professionals was said to require fundamental improvement.

“There is a lot of bureaucracy. It is true that documentation is needed, but in order to receive two pairs of orthopaedic shoes for my child, I have to go twice a year for a disability status check.” Kalina, mother, Bulgaria

“We have to go there again and again, and every two years doctors ask the same questions [...] although they already have all the documents in front of them.” Aelita, mother, Latvia

“I prefer not to go to social services and ask for anything, because this is too humiliating.” Izabelle, mother, Latvia

“Everything related to social services, that is everything you receive for free, is all about humiliation.” Leonid, father, Russia

Parents and service providers were worried that little or no support or information was available to families of disabled children. In Bulgaria it was reported that, although special programmes to help parents of disabled children existed (e.g. ‘Personal Assistant’), they were not available to many parents

“Once I read in a newspaper that I have the right to receive a nursing allowance. When I went and asked them in the social services office, they said they didn’t know anything about it. Only when I pointed to the article with my finger, they seemed to remember.” Ieva, mother, Latvia

“We can never receive support from these programmes [‘Personal Assistant’] ...because we are ‘so rich’.” Dona, mother, Bulgaria

“In Bulgaria very few things are done for finding such children, and telling their parents what they should do.” Lora, mother, Bulgaria

“There is very little information. If we – the mothers – ourselves do not go and show interest, nobody, not even a doctor, will inform us.” Bernadeta, mother, Latvia

Social workers explained that it was lack of knowledge of families and lack of resources, which affected the services they could offer.

“We can help, but it is difficult if they [the parents] don’t come here.” Lana, social worker, Latvia

“Our agency does not do anything – 8 leva [4 euro] for the telephone and double child allowances. This is not enough [for the parents of disabled children].” Margarita, social worker, Bulgaria

“Everything depends on accessibility of information. If I can give an answer – I help, if don’t know – what can I do?” Sabine, social worker, Latvia

“Social support should definitely be improved. We don’t even have a computer and [...] we have to beg the colleagues from next-door to use theirs sometimes.” Margarita, social worker, Bulgaria

Lack of co-operation between professionals taking care of disabled children was discussed by parents and service providers. Although within one organisation it appears satisfactory, co-operation between institutions seemed poor. Parents and service providers discussed the need for doctors to advise and help parents, for better co-operation between professionals and a more holistic approach to disabled children. At the same time, the need for more active involvement of parents was requested by some service providers

“At school the co-operation is quite good [...] We solve problems together.” Megija, teacher, Latvia

“There is no system which would integrate the child, his or her family and the therapy he or she needs.” Nadya, mother, Bulgaria

“The problem is that they [doctors, teachers, social workers] co-operate very little. We solve separate problems, but we lose the child as a whole.” Ilvija, doctor, Latvia

“The problem is that different specialists – teachers, doctors and social workers – work under different ministries. Co-operation should start at the ministry level.” Stefka, institution carer, Bulgaria

“The doctor gives the diagnosis, but he does not say where to go and what to do. There is no communication between the doctor and social services.” Astrida, mother, Latvia

“Parents should be more involved. Now we meet only twice a year. This contact should be more regular; not only when conflicts occur.” Larisa, social worker, Latvia

Education

Most of the children interviewed and participating in group discussion in all three countries understood that studying and a good education was particularly important for their future as a disabled adult. They were keen to take every opportunity for advancement. Overall they were content with their education and some were full of praise. Parents and service providers acknowledged that there were positive changes in the education system, particularly the inclusion of more disabled children in schools.

“I want to thank my teachers, who have been helping me to continue my education. Teachers who are so good and dedicated are seldom found.” Kolio (male), 13, home-living, Bulgaria

Parents of children with severe disabilities were concerned about the lack of special schools for their children. There was also the problem of transport to school which prevented their children from actually getting an education

“I have achieved many things by myself, because we also have faced the problem that there are no proper pre-school institutions for such children [children with severe disabilities].” Nadina, mother, Latvia

“There should be more centres.. in different regions ...both for the less and more severe disabilities.” Krasimira, mother, Bulgaria

“There are no institutions which would combine special teaching and special rehabilitation.” Alta, mother, Latvia

“This year my child has not attended school for three weeks altogether. It was not his fault – it was either the driver who was ill or the bus was broken.” Modrite, mother, Latvia

“There are children who are forced to sit at home because the money social services can give you for going to school, allows you to go only once a week.” Sabine, social worker, Latvia

Parents were also frustrated by the negative attitudes of some teachers and support staff to educational integration.

“She is doing fine mainly because of our efforts at home [...] She is getting little help from the teachers at school. Even if she [the teacher] decides to pay more attention to her, she considers it an effort that is not worth it.” Monika, mother, Bulgaria

"We have a psychologist in our school, who is good at working with able-bodied children, but doesn't understand disabled children, so she cannot help them." Larisa social worker, Latvia

"There are teachers for integrated education of children with impaired vision. They make great efforts: they communicate with the classmates of the child and the teachers. But I do not think these teachers receive much support from the ministry of education for example." Maria, mother, Bulgaria

Parents and children were aware of limited access to education beyond primary level. Access to universities seemed to be particularly problematic in Latvia and Russia. Lack of access to buildings and not taking the needs of disabled children into consideration were stressed as the most important obstacles.

"My child is now in the fourth grade of a special school. This school takes children up to eighth grade and the question is what we are going to do in four years time? [...] I will be forced to leave my job, which I respect, like and have studied for. Or, I will have to find someone to look after my child at home, if they do not open a place for children who cannot continue their education..." Nina, mother, Bulgaria

"Well, the special high schools they attend give them some professional qualifications; say, girls can study hairdressing, boys can become carpenters, etc., but we wish our children did much more." Sasha, mother, Russia

"I will never get there [into university]." Boris (male), 15, home-living, Russia

"Studying at university can be very problematic, because I'm in a wheelchair." Toms (male), 17, home-living, Latvia

"Universities should review their attitude to people with special needs. Now they don't do anything to make studying possible for disabled people." Leonards, teacher, Latvia

Improvements to the education system which were suggested by children, parents and service providers included: more vocational training, equal opportunities for University education, better access to computers, more materials for the disabled and more specialized support staff.

"For example textbooks in Braille, or some other materials – there are none." Villy (female), 17, home-living, Bulgaria

"They have difficulties using a pen... such children have problems with speech, so they cannot easily communicate by telephone. If they had computers, they would be able to communicate via the Internet." Katerina, mother, Russia

Those who provided education in institutions were concerned at the lack of integration with other educational institutions,

"Our school is like an oasis – children come here to study, but we don't know what happens to them later. We should have better co-operation with the other organisations." Asnate, institution carer, Latvia

Parents generally preferred their children to be educated locally either in mainstream schools or specialist education. There were many examples of children living in institutions because there

was no education for them locally near to their families. This was of concern for providers as well as parents.

“We began with Pytalovo as it was the only place but when a special school [for children with hearing disability] was opened in town, we moved... For our children Pytalovo is all fears. If we mention that institution [...] they are afraid.” Tania, mother, Russia

“He [the son] has been staying there [in an institution] for four years now, because we do not live close to the school and we cannot manage to go there every day and spend four hours commuting.” Rita, mother, Latvia

“There should be schools with classes for deaf children in every region so that a child can go home in the evening. Then there would not be a situation that a child does not see his parents for two weeks or more.” Megija, teacher, Latvia

Recreation and Leisure

Parents pointed out that after-school activities, youth provision and summer camps were necessary to allow their children to develop and integrate with other children. In terms of equalising opportunities, these activities are as important as formal education but there was little provided in the community. Access to leisure-time activities appeared better in institutions, where events and clubs for disabled children were organised, but with little contact with children or adults outside the institution.

“They take us to summer camps, theatre and different games.” Milen (male), 13, institution-living, Bulgaria

“Recreation and entertainment activities happen only because of parents’ initiative.” Dzintra, mother, Latvia

“[I wish] that I could take part in events, go somewhere where children who are not disabled can go.” Krista (female), 11, home-living, Latvia

“We can’t go out at all ... They watch us as if we were extraterrestrials [...] Where can we go with these wheelchairs? Children do not have fun.” Several parents, Bulgaria

“We once attended a concert - Korytovo centre organized the tickets. Children were brought in wheelchairs. There was no space to accommodate those wheelchairs, so we had to sit them under the stage next to the monitors.” Olecia, mother, Russia

“Why do summer camps not accept the disabled? Many are not well equipped. Say, they have no appropriate shower facilities. A healthy kid can wash his feet somewhere in a stream and use a hole as a toilet.” Anna, mother, Russia

“Children need a special car to go out and have fun. If we call the person from ‘Lozana’ company and say that we need the state provided special minPencho to take the children to ‘Patilantsi’ or to have fun, she will put the phone down on us.” Alexandra, mother, Bulgaria

The Disabling Environment

“Have you any idea why they [people with mobility disability] do not go out? Right, because there are no ramps and lowered kerbs.” Luda (female), 16, institution-living, Russia

For many participants this was too obvious a topic to be discussed at length. It was agreed that buildings and public transport were generally not accessible to children with mobility problems (particularly those in wheelchairs). There was a lack of appropriate signalling at crossings and no ramps or elevators for people with mobility problems. There was some special disabled transport in Russia, however quotas for the transport were seen as too low.

“We have a taxi provided by social services but this is not really of help because you are only allowed to use it once every two weeks.” Luka, father, Russia

“Old buses – all of them are a torture for people with mobility disorders. Without help of another person, it is impossible to move around in the city.” Leonards, teacher, Latvia

“There are only few pedestrian crossings with [audio-visual] signalling in Riga. That limits visually impaired people. That’s why they always have to feel dependent while being out in the street.” Asnate, institution carer, Latvia

“He cannot go to school because of the stairs.” Mariana, mother, Bulgaria

“We live on the fifth floor and when we want to go out, the elevator is broken. I need to take the child downstairs, find somebody to watch him, and then I go back to the fifth floor to get the wheelchair down. This is the usual procedure for a walk.” Irena, mother, Bulgaria

Rights of Disabled Children

The rights model of disability in relation to disabled children and their families suggests that the needs of all children are equally valued and important, and that the specific needs of disabled children are related to demands on public systems established to meet their human needs (Repkova 2005). In other words disabled children’s rights to live at home with their family, to have a good education, to have good health care and leisure and recreation opportunities are the same rights that are accorded to non disabled children. The disabling environment is the reason that there is not parity between disabled and non disabled children’s rights. Efforts of governments need to concentrate on finding the proper balance between the rights and responsibilities of parents on the one hand and the rights and responsibilities of children on the other hand and the special obligation of the State to protect children.

The difficulties for parents, children and providers in Bulgaria, Russia and Latvia were that laws concerning children rights already existed but they were not implemented or enforced. Both parents and service providers requested laws and legislations which already exist to be implemented. They agreed that the law was ineffective since it was not followed.

“The European Parliament should say that laws ought not only to be written and passed, but they should also be applied. This does not happen in Bulgaria.” Milen, father, Bulgaria

“[Tell the politicians] to put things into practice. There are parts of the law which have not yet started to function.” Stefka, institution carer, Bulgaria

“I would like that they [politicians] would follow the rules which exist. The rules are not bad.” Amanda, mother, Latvia

“Rights for disabled children are [there to] to help them be integrated in society; feel as the able-bodied; not worse.” Einars, institution carer, Latvia

“According to me, disabled children in Bulgaria, and disabled people in general, have no rights at all. They only exist on paper.” Nadya, mother, Bulgaria

“Rights are not respected in society. Someone who refers to rights is often regarded as a yammerer. Instead, an individual negotiation [...] achieved with the help of a bribe, is often very much respected.” Xenia, social worker, Russia

“They [the laws] are very good if they are followed. They are not known and they are not respected. Parents don’t have information about the rights of their children.” Dora, teacher, Bulgaria

“The biggest problem is that there is no information on what our legal rights are. I have received all the information about my daughter by chance, from strangers.” Nadya, mother, Bulgaria

“The law is very good but void – no-one bothers..People are not used to appealing and referring to rights when they need something or defend themselves.” Violetta, mother, Russia

Progress since Transition and what still needs to be done

Parents and service providers in all three countries commented on some positive improvements after the transition to mixed economies in the 1990’s. This included some integration in schools which had now improved attitudes of children in those schools to disabled children in the communities. There were some improved access to appropriate services but in all three countries, parents and providers felt there was a lot still to do.

Parents reported that it was personal determination which was the main factor helping to raise a disabled child at home. In order to encourage more children to live with families, parents suggested that more support from the state paired with better working conditions for them (more flexible working hours and better earnings) was necessary. Service providers mentioned the need for better financial support as well, but also talked about attitudes towards disabled children in society, which needed to improve to allow more children to live with their families

“Parents should be able to provide care at home. I would like them to have a day-care centre to drop a child, if necessary, for a day, weekend, a holiday. Holiday activities and joint activities for children and the same for adults, not only those odd family get-togethers. Be honest, take them seriously.” Maya, nurse/therapist, Russia

‘It is crucial to improve living and working conditions for parents; centres like Korytovo and computers with Internet for children can solve more than a half of all problems! Children will get education and parents will get time off.’ Xenia social worker Russia

Recommendations

Parents, providers and children had many positive and useful solutions to the difficulties they faced. They included: gradually transferring resources from institutions to families, flexible working hours and better earnings, more specialist support, integrated schools, day centres and summer camps, the provision of respite care and changing attitudes in society towards disability. By focusing on the views of users and providers of services who have had many years of experience of these issues, a grassroots perspective that is practical and needed in terms of action on disability can be provided. They illustrate what changes children, parents and professionals believe could positively benefit them in their countries. The policies, proposals and programmes suggested here aim to prevent family disability – that is the family as a whole being disabled, not by the ‘burden’ of a child with disabilities but by the burden of inadequate finances, no respite or alternative care, inaccessible buildings and poorly planned or non-existent day care, transport and leisure facilities (see Diagrams I and II).

The main issues to be considered are:

- Hearts and minds – changing attitudes to the disabled in the medical profession, in institutions and in communities
- the development of visible practical support for families with children with disabilities in the community so that other families will be encouraged to support disabled children
- the development of community support for parents so that newly born and young children diagnosed as disabled can be looked after in the family
- the re-introduction of children into families and/or communities – either their families of birth or fostering or adoptive families
- the integration of young people into communities so they can live as independent adults
- Consideration of institutions – do they need to be abolished or can they be modernised? (See Model I for an illustrative example).
- Can such institutions become Family Centres for the Disabled? – what are the resources for the localities?
- The balancing of resources, the management of staff and preparing for change. Those already in institutions should not be disadvantaged any more than they already are – while transferring future funds to the community. These changes are more likely to be achieved if well prepared in advance and led by local initiatives.

Conclusion

‘States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information ... (in relation to disabled children) .. including dissemination of and access to information concerning methods of rehabilitation, education and vocational services with the aim of enabling States parties to improve their capabilities and skills and to widen their experience in these areas’. Article 23.4 of the Conventions on the Rights of the Child

Many countries in Eastern Europe saw the collapse of the old totalitarian regimes as an opportunity for a new start – particularly for children living away from home. However despite 12 countries having specific laws on people with disabilities, six having laws on Children’s rights or protection and 12 having education laws with specific mention of disability or special education, little has changed for children with disabilities – either those at home or those in institutions.

Since the mid 1990’s, the child population in institutions for the disabled has stabilised rather than decreased in Russia, while in the Czech Republic, Armenia, Turkmenistan and Uzbekistan, there are more children with disabilities in specialised institutions in 1999 than a decade earlier (UNICEF 2003, Report 8). This is not the intention of these countries’ laws and policies, nor fits with the UN convention on the rights of the Child seeing out- of- home care as a last resort. However implementation of policies on supporting children with disabilities at home has proved problematic.

These positive policies and programmes are designed to encourage innovative thinking in relation to children with disabilities. Although many countries in Eastern Europe are extremely poor, resources may be able to managed in different ways in order to progress care in the community for disabled children. Practical programmes that can be acted upon are likely to be useful for Government policy makers, Directors of NGOs and all those responsible for children with disabilities programmes in Eastern Europe.

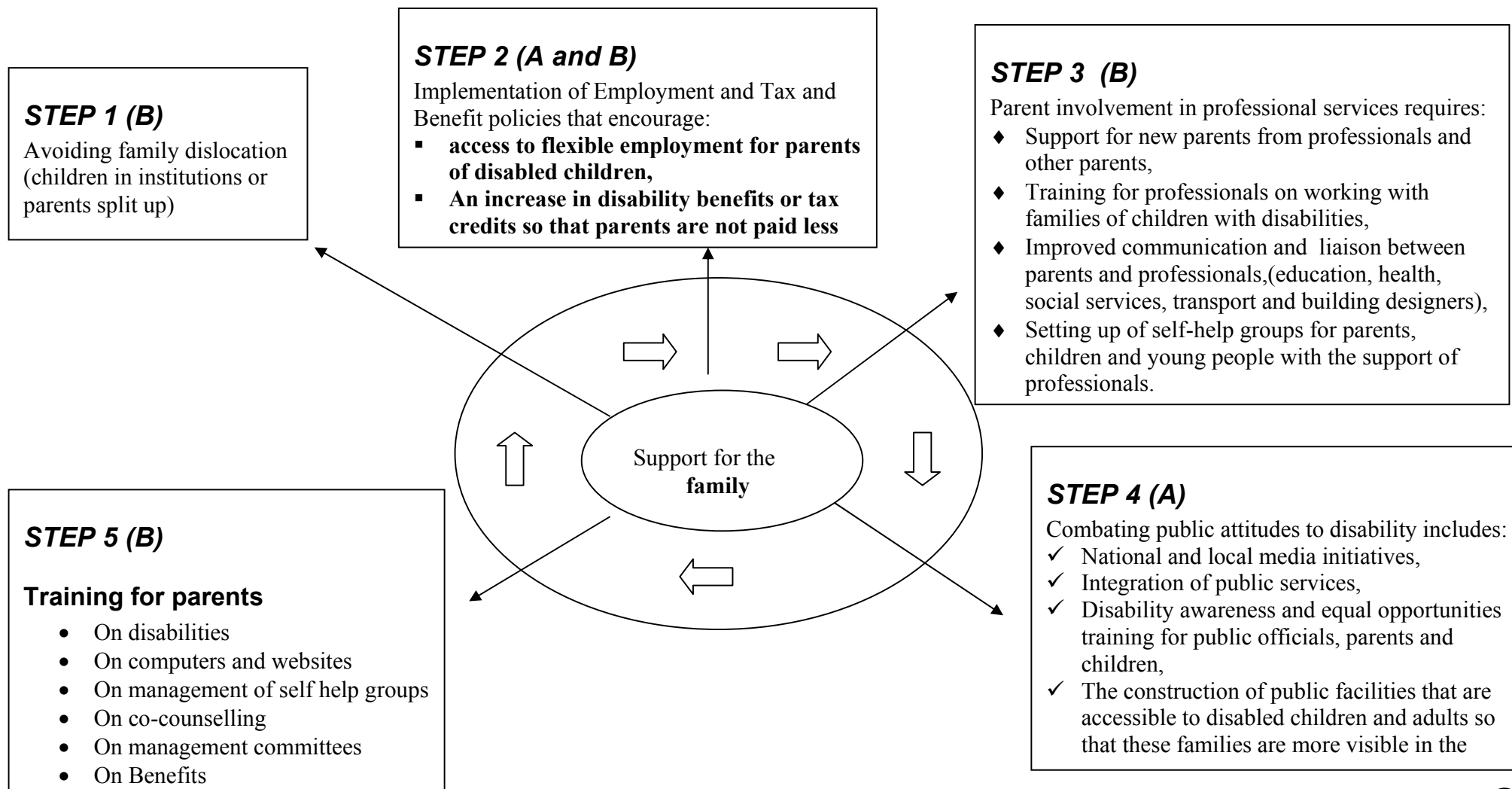
This large scale qualitative study has revealed the problems, issues and frustrations of being a disabled child or caring for a disabled child in Bulgaria, Russia and Latvia. While not representing all disabled children in CEE and CIS countries, it highlights what it is necessary to overcome if disabled children are to enjoy the same opportunities and rights as other children.

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DIAGRAM 1
Five Step Programme to Support Children and Young People with Disabilities in the Community



Key to support requirements A and B

'Children at Risk in Central and Eastern Europe' (UNICEF Regional Monitoring Report 4) identifies the twin pyramids of mounting risks for children and their support requirements. The family and support measures are categorized as A- Universal family services and child benefits and B – Specialised family support services (RMR4,1999, FIG IV.3, P102, UNICEF).

DIAGRAM II

Children and Parents must be the primary stakeholders of disability initiatives

Public information:

Information using government, local government and NGO websites for disabled families. Private sponsors of self help websites and radio stations. Local information on facilities/support in public places. Awareness campaign tv/media/public information

Housing:

Restructuring of institutions into smaller units. Private house building to include some social housing.

Transport:
From institutions to communities and from communities to institutions to encourage integrated education, independent housing, vocational training, leisure and work opportunities.

STAKE HOLDERS NEEDED?

Access to public buildings:
Universities, schools, nurseries, housing, employment and leisure facilities.

Multi-disciplinary co-operation:
Training, conferences, joint funding initiatives, shared information and good practice in consultation with parents and young people.

Resources for care in the community:
Movement of funds for disabled children so that no new applications to institutions. Funding transferred to families via benefits and tax credits and community support services

Tax benefits:
For companies and private individuals who contribute to community programmes for disabled families.

Education and Employment Services:
Access/ integration for disabled children, International/ national vocational training initiatives for young people with disabilities, employment laws to promote engaging young people with disabilities enforced.

MODEL 1 A FAMILY CENTRE FOR CHILDREN WITH DISABILITIES

